Feasibility of Patient and Public Involvement (PPI) in all aspects of establishing a Survivorship Programme.

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Introduction

The patient voice in research is imperative. Those who have lived experience of a disease treatment have a unique lens in recommending improvements to a service (1). It is well recognised that early adoption of PPI ensures that research focuses on issues relevant to patients and the public(2). In September 2020, The Mater Misericordiae University Hospital (MMUH) and St Vincent's University Hospital (SVUH) were successful in securing research funding from the Irish Cancer Society Women's Health Initiative (WHI). The WHI aims to improve health and wellbeing for women during the survivorship journey. The Living Well Cancer Programme is the name given to the group and it consists of professionals specialising in gynaecological oncology. This programme aims to include the patient voice in all aspects of the project.

Methodology

With the help of PPI, the team identified three key projects:

The Menopause After Cancer Study (MAC Study) is a multi-modal, technology assisted intervention designed to support women who are experiencing debilitating menopausal symptoms after or during cancer treatment who cannot use hormone replacement therapy. It involves the use of non-hormonal pharmacotherapy, digital cognitive behavioural therapy for insomnia and access to information about self management strategies for common symptoms of menopause as well as the identification of a partner or support person to try and improve quality of life over a 6 month period.

The thisisGO.ie virtual platform offers a single repository of evidence-based resources and clinical information for women affected by cervical cancer and their families. It includes more than 130 different articles as well as videos and audio content addressing issues encountered at every stage of cancer diagnosis, treatment, and life with and beyond cancer.

The Gynecological Oncology Cancer Centre (The GO Cancer Centre) was established in both MMUH and SVUH. The GO Cancer Centre's are supported by a multidisciplinary team and open to women affected by any gynaecological cancer. The **Diagnosis Delivery Study** was rolled out at the Centre. It includes the Diagnosis Delivery Card and the Diagnosis Image to represent that survivorship starts at diagnosis and to empower and educate newly diagnosed women.

Patient and Public Involvement

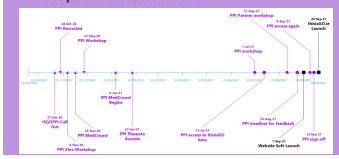
MAC Study

An external company called MedCrowd moderated a closed online group of 14 participants affected by breast and gynaecological cancers. The group ran from January to mid February 2021. Each week separate questions were asked. The structure allowed for text-based conversations to gather insights from participants about different aspects of survivorship. The lack of information about menopause and how to manage its common symptoms emerged as a strong theme, especially for those who were not eligible for HRT. From this, the MAC study was born.

thisisGO.ie

In November 2020, volunteers with a current or prior diagnosis of cervical cancer were sought from within the membership of the Irish Society of Gynaecological Oncology Patient and Public Involvement group (ISGOPPI). Several workshops were held to explore how an online platform could support these women. Using Interpretive Phenomenological Analysis a series of themes emerged which informed the content for the platform. PPI was central in every aspect of the project including web design and software testing.

PPI Participation in thisisGO.ie - timeline

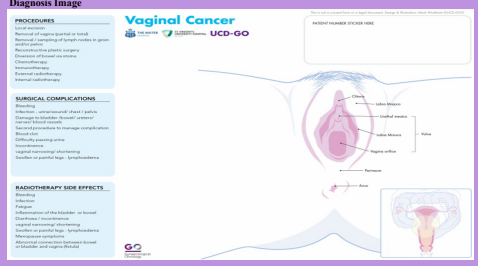


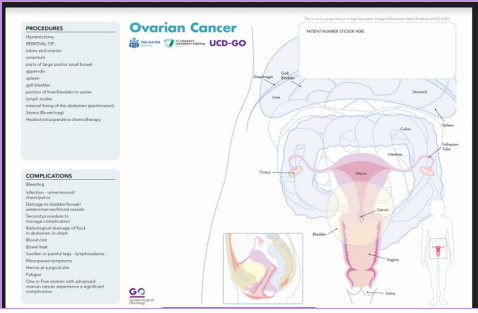
The GO Cancer Centre/Diagnosis Delivery Study

Survivorship begins at diagnosis. Supporting patients at this stressful time was an area that the team were keen to explore. The concept of the **Diagnosis Delivery Card** began in October 2020. A workshop took place in November 2020 with more volunteers from within the ISGOPPI. The participants supported the concept and helped shape the information that was included on the card. During this workshop one of the participants disclosed that she had been given a hand-drawn image of her cervix at the time of diagnosis which indicated the extent of the cancer. Other volunteers disclosed that some of their surgeons had also drawn pictures in their charts, however, they did not get to take it home. There was a consensus among the volunteers that it would have been very helpful to have these diagrams to refer to after the consultation. From this, the team designed the **Diagnosis Image** for all five of the gynaecological cancers.

Diagnosis Delivery Card

Diagnosis Image





Progress to date

MAC Study

Recruitment opened in late June 2021 and to date 100 of an intended 205 participants have been enrolled. Social media has been employed to great effect to drive recruitment to the study. Given the current trajectory of recruitment, we expect all participants to be enrolled by late January 2022 with complete data available by July 2022.

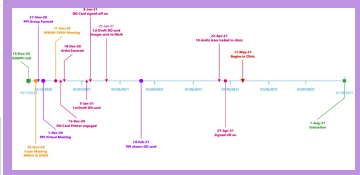
thisisGO.ie

The thisisGO.ie platform was launched on World GO Day September 20th 2021. There has been a phenomenal response from patients, partners, health care professionals (HCP), the general public, mainstream and social media. Phase one of thisisGo.ie provides a safe and accurate repository of information for women, their partners and HCP about cervical cancer. This includes basic information about the disease itself as well as complications associated with treatment and the long and short term impact of cervical cancer. The site has been visited more than 1500 times since launch.

> "I just want to say thank you for developing this wonderful, excellent and informative website…It is very important that patients have somewhere reliable to seek information rather than relying on Google which can lead you up the wall at times"
>
> *Patient feedback October 2021*

Diagnosis Delivery Study

The feedback for the card and the images has been overwhelmingly positive both from patients and physicians. Both are now used throughout the disease trajectory as a visual and practical aid during consultations. Other hospital settings have expressed an interest in adopting them. Currently this aspect of the programme is being evaluated through semi-structured interviews as part of a quality improvement initiative.



Conclusion

The Living Well Cancer Programme, has been heavily influenced by PPI in all its projects. We have found that PPI has provided rich context to the projects we are undertaking. Feedback so far has been positive.

In the course of this initial work, we have identified a potential limitation of PPI that it is important to be aware of. When we asked our participants to review content on thisisGO.ie or provide feedback on any other aspect of our work, we found that they tended to focus only on the material that was relevant to their own personal experience of the disease in question. This affects how comprehensive any PPI may be and places an onus on us as professionals to recruit individuals with differing treatment experiences, which can be challenging.

Nevertheless, PPI is an essential element in approaching the development of any new clinical service, within the cancer sphere or otherwise.

"Nothing about me, without me"

References:

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